BODILY DISTRESS SYMPTOMS IN CHILDREN AND YOUNG PEOPLE

A **GUIDE** TO ASSESSING AND MANAGING PATIENTS UNDER THE AGE OF 18 WHO ARE REFERRED TO SECONDARY CARE

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

This Guide is endorsed by the Royal College of Psychiatrists (RCPsych) and the Paediatric Mental Health Association (PMHA).

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This is the second iteration of this guide. It was revised in 2022 in consultation with the Executive Committees of:

- Royal College of Psychiatrists Child and Adolescent Faculty (RCPsych CAP)
- Paediatric Mental Health Association (PMHA)

WHO IS THIS GUIDE FOR?

This is a clinician-focused guide, designed primarily for secondary care doctors and the wider MDT, provides advice and helpful tools for the assessment and management of children and young people (CYP) with bodily distress symptoms. The aim of the guide is to ensure healthy relationships between the care provider (staff, as well as institution) and care receiver (CYP and carer/s) and to minimise the risks of recurrent presentation, including missed educational time and inadvertent medical child abuse. This is a complex and difficult area, where clinicians need to hold uncertainty and anxiety both from parents, families and themselves. We encourage use of this guide by the MDT for complex cases, which we feel always benefit from multiple perspectives and supervision.

WHEN SHOULD I USE THIS GUIDE?

This document will be most helpful to those involved in the identification and management of CYP with bodily distress symptoms, particularly those working without access to expert advice. Regardless of service set up, seeking direct input from the paediatric mental health lead, senior paediatric colleagues, and, if available, under 18s mental health clinicians, will always be advisable over sole use of this guide.

HOW SHOULD I USE THIS GUIDE?

This guide is designed to be read in sequence, as it covers a number of steps in the identification and management of BDS. We would prefer you to read and think about it page by page. However, it may be that you need to use this guide in less leisurely circumstances.

If you are just about to see someone who you think might have BDS, go to step 2.

If you are involved in the care of someone who is under investigation for BDS, go to step 3.

If you have someone on the ward or in clinic with a bodily distress presentation, consider whether step 4 has happened, and if so, go straight to step 5.

If you are thinking about how to organise services around a CYP with BDS, step 7 might help you.

If you are looking for resources, a leaflet or letter templates, go to Appendix 4, 6, and 5 respectively.

If you have read this before and are looking for a summary to refresh your memory, go to Summary and How To.

This guide is written by clinicians, for clinicians. It is not an exhaustive research review. Its primary purpose is to be a safe and practical aid.

A DISCLAIMER - CHILDREN AND YOUNG PEOPLE'S STATISTICS AND DATA

There is unfortunately limited data looking at medically unexplained or functional symptoms, or more recently at bodily distress symptoms in CYP populations, therefore some of the statistics used in this guide will refer to adult populations**, this will be clarified in the text where necessary**.

VERSION 2

As a CAMHS Liaison Psychiatry team we have reviewed our previously published **guidelines on managing medically-unexplained symptoms for paediatricians** and other non-psychiatric colleagues managing children presenting with these difficulties. We would like to present our **updated** guide on recognising and managing medically-unexplained symptoms.

Updates

1. We have brought our guide in line with current research and thinking by changing from using the term medically-unexplained symptoms to **bodily distress symptoms** and bodily distress disorder
2. We have **defined these terms** for clarity in our introduction and briefly explained and evidenced this change
3. We have streamlined and **reduced** our discussion around changing terminology in this area
4. Given the recent Perplexing Presentation and Fabricated or Induced Illness guide released by RCPCH, we have significantly reduced this section, **removed this overlap** from our guide, and have **linked** to the PP/FII document directly
5. We received significant criticism for the language used in our FII section previously, **this has been removed**, and the language used in our guide has been updated to address this
6. We have **updated the referenced evidence base** for our guide in line with current research and understanding
7. This guide has **been reviewed by the executive board of the PMHA** and we have made alterations to bring our document in line with their feedback

INTRODUCTION

WHAT IS BODILY DISTRESS? WHAT IS BODILY DISTRESS DISORDER?

The term bodily distress describes a broad range of clinical presentations, rather than a diagnostic condition in its own right. The symptoms an individual experiences (from bodily pains through to loss of neurological function) are not explained by physical examinations or investigations alone. However, symptom experience is no different from that arising in the context of known pathology; symptoms are just as real and are certainly no less anxiety-provoking.

Bodily distress symptoms (BDS) and bodily distress syndrome have become widespread terms since first defined in 2007, as practice has moved away from medically-unexplained symptoms (MUS), and BDS has become an umbrella term for the many overlapping functional syndromes and somatoform disorder.(1-3) The ICD-11 has now defined Bodily Distress Disorder as the presence of distressing symptoms that cause excessive attention or preoccupation to be given to them, and may result in multiple contacts with healthcare providers.(4) These bodily distress symptoms meet ICD-11 criteria for the disorder when they are present on 'most days for at least several months', and is not alleviated by 'appropriate clinical examination, investigation, and reassurance'. However, this guide will use bodily distress symptoms as the acronym BDS to disambiguate from the BDD acronym as Body Dysmorphic Disorder.

Experience of bodily distress symptoms are common and affects around one in four children to some extent. This can range from mild, transient physical symptoms to a severe, debilitating, and enduring disorder. These symptoms can be persistent and distressing in up to 10% of children and adolescents, and the same proportion have a significant functional impairment.(5) The symptoms should be taken seriously, and a range of services need to be available to Children and Young People (CYP) with these problems. We also know that bodily distress symptoms can occur alongside a physical disorder e.g. non-epileptic seizures in someone with epilepsy, or abdominal pain in excess of pathology, in someone with inflammatory bowel disease.(6)

We have written this guide for medical professionals to help them manage the uncertainties of this complex area, and with holding this uncertainty for themselves where diagnoses feel unclear or even unhelpful.

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1 Fink et al (2007) Symptoms and syndromes of bodily distress

2 Fink and Schroeder (2010) One single diagnosis, BDS

3 Ivbijaro et al. (2013) BDS: the evolution from MUS

4 WHO (2019) ICD11

5 Rask et al (2018) Chapter 4 – Factors and course of functional somatic symptoms

6 Fobian and Elliott (2019) A review of FND

WHAT ARE THE IMPLICATIONS OF DEVELOPING BODILY DISTRESS?

For some CYP, bodily distress will resolve spontaneously (see Table 12 in Appendix 1). However, some will develop chronic symptoms and the mainstay of their treatment will be symptom control.

From research in adult populations, it is known that bodily distress presentations cost the NHS significant amounts of money (£3.1 billion per annum in 2020).(7)

Primary care clinicians play a vital role in managing bodily distress and this work needs support and acknowledgement by those working in secondary care. Approximately 30% of adults with BDS seek direct healthcare support, of which only 1% present to secondary care.(8) This adult group present frequently, to multiple specialities and often undergo extensive and unnecessary physical investigations, and even treatment – something we've long understood as leading to a significant risk of iatrogenic harm.(9) Similarly, 30% of children with BDS will present to primary care(5), and are therefore likely to also be at risk of this iatrogenic harm.

For the purpose of this guide, the term bodily distress has been used to allow inclusion of all CYP who present with medical symptoms lasting three months or longer, where symptoms are causing a significant amount of distress, disability and help seeking. This includes:

1) CYP who require ongoing diagnostic work up for a possible underlying physical illness
2) CYP where an underlying physical cause has been sufficiently excluded, but the symptoms persist and are causing significant disability
3) CYP who have a diagnosed physical illness in whom symptom levels are inconsistent with underlying pathology and / or who have additional unexplained physical symptoms in other body systems

Because of the frequently changing and charged nature of the terms used to describe and categorise various types of bodily distress, this guide no longer covers the debate around terminology.

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5 Rask et al (2018) Chapter 4 – Factors and course of functional somatic symptoms

7 Leaviss et al. (2020) Behavioural modifications for MUS

8 Rosendal et al. (2007) Classification of MUS

9 Fink (1992) Surgery and medical treatment in persistent somatizing patients

STEP 1: OPENING YOUR MIND TO THE POSSIBILITY OF BODILY DISTRESS SYMPTOMS

Just as some CYP and their families may be more inclined to perceive bodily symptoms as indicative of exclusive underlying physical disorder, so too may some doctors. Recognising that you are someone who is more comfortable having conversations based on the known, rather than unknown, may be a prompt to make yourself consider BDS early on in your assessment process. Doctors managing their own anxiety, or that brought to them by their patients, by ordering *another* investigation or referring on to a specialist is a well-recognised phenomenon in the NHS.

Think about BDS if:

1) Your patient has undergone an unusual level of investigations and/or been to a significant number of hospital specialists relative to their diagnosis (remember BDS can also occur in the context of organic pathology e.g. non-epileptic seizures alongside epilepsy)

2) You experience a high level of anxiety when seeing the patient and their family, and/or feel pressured into referring for investigations or to other specialists in a way that you don't experience with other patients with similar clinical presentations and test results

3) There is a family history of bodily distress presentations (drawing a quick three-generational family genogram and plotting all illnesses across the generations is never time wasted in any clinic setting)

4) There is significant absence from school as a result of symptoms that appear 'out of proportion' to physical investigations

5) You are concerned that a parent/carer appears overly invested in their child's illness and loss of function, remembering that for any of us, child or adult, there can be secondary psychological gains which come from being ill, whether this is time away from things we find stressful (school/work/socialising) or the extra attention and sympathy that is conferred on someone ill

6) There has been a previous illness event but there are residual or ongoing symptoms out of proportion to expected recovery, or disproportionate anxiety around these from parents or child

STEP 2: BEGINNING THE CONVERSATION

In an outpatient clinic, or inpatient setting, introduce as early as possible the fact that emotionally-driven mechanisms are often closely linked to bodily responses – tears coming out of our eyes when we are sad, our bodies rocking and making a noise as we laugh at a joke. You might also point out how normal it is to get sweaty palms or a dry mouth when nervous, or to get abdominal pains or headaches when stressed.

As you order investigations, prepare the CYP and their family for possibly 'normal' results, and make clear that, even if this is the case, 'normal' results do not detract from/invalidate their experience of pain/tiredness etc.

Provide plenty of informal (chatting away as you examine the CYP) psychoeducation on the connection between body and mind e.g. that even at a cellular level our immunity goes down when we're sad and depressed.(10, 11) Equally that many of our figures of speech derive from this knowledge e.g. "I felt sick with shame", "It felt like a real kick in the stomach/guts" i.e. when something really disappointing happens.

Communication Tips

- **Share your uncertainties** with the CYP and their family about their condition

- **Do not focus** on finding a diagnosis

- **Listen** to what the CYP and family **wants**; explore their concerns. They may not want investigation and may just require reassurance

- Remain **non-judgmental**; the CYP is genuinely experiencing the symptoms

- **Pre-empt normal test results** and explain what you expect to rule out

- Explore **early** on how the CYP's symptoms **affect their mood** and vice versa

- **Normalise the impact** that stress can have on symptoms e.g. muscle overuse/tension causing back pain

During the consultation, explore the connection between the CYP's mood and their symptom severity. Get a feel for whether their symptoms are worse at times of stress, but also ask directly whether e.g. exams/fatigue worsen their symptoms.

You might feel it is your role to rule out a physical cause **before** addressing the mental health aspects of the case. However, as well as delaying the process of addressing the anxiety generated by the symptoms, this can create a very unhelpful dynamic and gives the impression that body and mind are two separate systems that can be treated consecutively, rather than need to be treated as a whole.

In one-off emergency settings, you may need to operate a little differently. If you note that the CYP has had multiple attendances, raise this with colleagues and make sure someone has talked with the CYP and their family about how bodily feelings are often an important communication about

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10 Dhabhar (2014) Stress and Immune Function

11 Kiecolt-Glaser et al. (2002) Depression and Immune Function

the state we're in i.e. about our emotions (body distress); tell them this is something you see a lot in the emergency department (ED). Warn them that frequent emergency presentations with physical symptoms can result in medical harm if staff aren't alert to the possibility of an emotionally driven component to these symptoms.

Offer to connect them up with paediatric psychology or a paediatric liaison service, or simply offer to talk to their GP about needing to think a bit more with them about what might be contributing to these frequent presentations to the ED. In some areas, CAMHS services might accept a referral for bodily distress, however in many cases, unless there is clear evidence of significant mental health difficulties, such a referral is likely to be declined.

If possible (and it may not be) offer to see the CYP and family alongside a mental health colleague. This makes it clear to the CYP and their family that you are seeking help with **your** understanding of their situation, and that you are not simply 'getting rid' of them to someone else. Most importantly they then see mind (mental health) and body (child health) working closely together **in the same room** and can begin to appreciate the connectedness between mind and body themselves. In terms of explaining why you are involving your mental health colleague/s, if bringing mind and body together to think together seems an insufficient rationale for the family, you can also frame requesting mental health input as akin to ordering another 'investigation'.

STEP 3: MAKING SURE YOU DON'T FALL FOUL OF UNDER- AS WELL AS OVER-INVESTIGATION.

As we have said, when you order investigations, prepare the CYP and their family for possibly 'normal' results, and make clear that, even if this is the case, 'normal' results do not detract from/invalidate their experience of pain/tiredness etc.

PERFORMING RELEVANT BUT FINITE PHYSICAL INVESTIGATIONS

Adult data shows that between 4 and 10% of patients who present with somatic, non-organic symptoms are subsequently found to have an underlying medical illness.(12) With this in mind, it is important that all basic investigations are performed in any CYP who present with BDS.

The type of investigation will depend on the presenting symptoms, but should always include a full history, physical examination and routine blood tests. If these tests results are normal, then at this point you should consider whether any further investigation is required.

This can be a tough decision to make, which may be helped by considering whether there are any sinister signs or symptoms accompanying the presentation. Tables 2 to 6 give some examples, laid out by body system, with red flag symptoms and key diagnoses that may masquerade as BDS.

Colleagues have suggested the phrase 'Yes, I can arrange this scan/test, but I think it is likely to be normal. What shall we do then, as your child will still have these troublesome symptoms?' as a helpful way to open this discussion.

It is important to note that investigating bodily distress is a dynamic process. Symptoms may evolve or change over time. Don't be afraid to restart the process of reinvestigation should the CYP's symptoms change and 'red flags' develop.

NOT INVESTIGATING UNNECESSARILY

Amidst the uncertainty and anxiety generated by BDS, many CYP fall victim to over- as well as under-investigation.

Doctors dealing with CYP with BDS often feel pressurised into performing unnecessary investigations by CYP and/or their families. Studies show that performing investigations where there is a low index of suspicion for underlying pathology does not reduce an individual's anxiety about their BDS.(13) The only result is a small reduction in further visits to primary care.

Furthermore, sending off a battery of investigations may identify minor non-specific and insignificant findings that may impede rather than helpfully support decision making. One study

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12 Chitnis et al. (2011) Guidance on MUS

13 Rolfe and Burton (2013) Reassurance after diagnostic testing

14 Jordan et al. (2010) Brain MRI in SCD

looking at MRI findings in CYP with sickle cell disease identified that 6.6% yielded incidental intracranial findings.(14)

So, when considering whether to perform an investigation, consider whether the perceived benefit of the investigation (factoring in the pre-test probability) outweighs the associated iatrogenic harm, economic impact, and possible delay in shifting the focus from diagnosis to symptom management. If you do decide to investigate further, rather than creating the impression that you expect to find underlying organic pathology, pre-empt normal test results and start to prepare the CYP and family for the possibility of BDS being the 'end point' of investigations.

If you continue to question whether further investigation is necessary, and/or you are experiencing pressure from the CYP or their family to do so, utilise the wider team and other colleagues for support and advice, and consider requesting a second opinion. It is important for doctors to protect themselves as well as their patients. Document clearly what you have chosen to investigate, why you have chosen not to order other tests, what you have told the CYP and family and record the absence of relevant 'red flags'.

CONSIDER FUNCTIONAL OVERLAY IN DIAGNOSED PHYSICAL CONDITIONS

After an illness event, there can be development of BDS when we see the persistence of symptoms after the resolution of a physical cause – for example after an infection. Persistence, disproportionate physical symptoms, or disproportionate stress or anxiety may indicate a functional overlay of BDS.

This is often seen in neurology. Around one third of adult patients who present to neurology outpatient settings are felt to have a functional component to their presentation.(15) NEAD is an especially common presentation.

The prevalence is felt to increase with age and general estimates vary between 1-9% of children with suspected epilepsy.(15) Due to the understandable anxiety that a seizure presentation can provoke in carers and professionals, the potential for iatrogenic harm is significant. This can occur as a result of multiple investigations being performed, with many CYP spending years on unnecessary antiepileptic medication before an accurate diagnosis is made. Interagency working (child health, neurology, family, school, CAMHS, paediatric liaison and possibly social care) is key to avoiding serious misdiagnosis of NEAD as epilepsy.

For a proportion of CYP with a diagnosis of epilepsy, NEAD may also co-occur. This is often described as a 'functional overlay' i.e. the presence of bodily distress symptoms in addition to known pathology in the same body system. This is frequently seen in many other long-term conditions such as sickle cell disease. In these cases, which are inevitably complex and challenging, it is important to identify and highlight the existence of this phenomenon to the CYP, family and professionals, and careful and collaborative interagency working is crucial to avoid over-prescribing and unnecessary time off school.

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15 Reilly et al. (2013) Psychogenic seizures in children

IDENTIFYING UNDERLYING MENTAL DISTRESS AND CONSIDERING MISSED DIAGNOSES

Make sure your own lack of familiarity with diagnosing/ascertaining particular conditions (e.g. autism, anxiety or depression) does not mean they get missed and left untreated. On average, 10-30% of all patients who present with BDS have an underlying psychiatric diagnosis.(12)

Always work alongside paediatric liaison, psychology or CAMHS colleagues if they are available. If not, consider using screening tools such as the RCADS[§] or SDQ[**] and then referring on. These detect likelihood of conditions like depression, anxiety, panic disorder. It is important to be mindful, however, that these screening tools are rather blunt instruments in patients with physical symptoms. Patients with bodily distress tend not to report overt mental health symptoms precisely because their distress is expressed in bodily form (hence the older term 'conversion' or current one, bodily distress disorder).

A note of caution: separate work by off-site teams never tends to work as well as co-located work between child health (including physical therapies) and mental health, so make sure you work hard to maintain close links with each other, if colleagues are distant from your practice/hospital.

TABLES – SYMPTOMS AND RED FLAGS BY SPECIALTY

Here we list the common presenting symptoms CYP may come to each specialty with, and the red flag symptoms that need further investigations. Physical symptoms can mask psychiatric pathology (such as with dysphagia and eating disorders) so it is important to consider the two in parallel.

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12 Chitnis et al (2011) Guidance on MUS

[§] https://www.corc.uk.net/outcome-experience-measures/revised-childrens-anxiety-and-depression-scale-and-subscales/

[**] http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz(UK)

Table 1: Neurology

Symptom	Red flags	
- Headache - Dizziness - Fits i.e. non-epileptic seizures - Faints i.e. LOC/collapse - Amnesia - Visual disturbance - Tinnitus - Paralysis/going off their legs/muscle weakness	- Pyrexia - Anaemia - Night sweats - Absent tendon reflexes - Family history of neurological disorder - Neurocutaneous stigmata e.g. axillary freckling, café au lait spots on examination	- Bladder/bowel dysfunction - Skin pigmentation - Focal neurology - Ear discharge - Hearing loss - Nystagmus - Papilloedema

Table 2: Cardiology/Respiratory

Symptom	Red flags
- Shortness of breath - Palpitations - Chest pain	- Dysphagia - Anaemia - Weight loss - Pyrexia - Night sweats - Loss of consciousness

Table 3: Gynaecology/Urogenital

Symptom	Red flags
- Dysuria - Polyuria / incontinence - Dyspareunia - Dysmenorrhoea - Menorrhagia	- Anaemia - Pyrexia - Weight loss - Night sweats - Precocious puberty - Haematuria-micro/macroscopic - Abnormal vaginal discharge

Table 4: Rheumatology/Musculoskeletal

Symptom	Red flags
- Back pain - Joint pain - Pain in arms/legs - Persistent / recurrent fever	- Thoracic spine pain - Pyrexia - Weight loss - Night sweats - Anaemia - Focal neurology - Joint restriction, persistent morning stiffness > 15 minutes - Overlying skin erythema, rashes or skin pigmentation on examination

Table 5: Gastroenterology

Symptom	Red flags
- Vomiting - Abdominal pain - Dysphagia - Nausea - Bloating - Diarrhoea	- Weight loss - Anaemia - Night sweats - Haematemesis - Pyrexia - Blood in stool - Tenesmus - Steatorrhea - Strong family history of pathology - Rapidly progressing symptoms - Skin manifestations on examination e.g. dermatitis herpetiformis, pyoderma gangrenosum, erythema nodosum, granuloma annular

STEP 4: CREATING CHRONOLOGIES, LINKING WITH OTHERS, EXPLORING PSYCHOSOCIAL FACTORS AND SAFEGUARDING

CREATING A CHRONOLOGY AND LINKING WITH OTHERS

For all CYP who present with bodily distress, it is vital to take a comprehensive social history covering home and school life, as well as peer relationships. This provides a more contextualised understanding of the CYP's symptoms and their meaning within, and impact on, the family. Table 6 outlines various social stressors that are important to screen for early on in the assessment process.

You should also take a detailed developmental history. Bodily distress can be associated with sensory hypersensitivities, so neurodevelopmental disorders like autism should be considered. These hypersensitivities are commonly thought of in the visual/audio/tactile domains, but may also extend into interoceptive senses prompting distressing interpretation of these signals. In autism, alexithymia (a difficulty in detecting, understanding, and expressing one's emotions) is common. Alexithymia has been consistently linked to higher incidence of MUS in adults, and some research suggests this in children although the picture is less clear, partly due to more heterogenous methods of assessing alexithymia.(16) Nonetheless, we understand BDS as a way of expressing psychological distress where CYP would struggle to express this verbally.(17) Under such circumstances, it makes sense that the child's body might do the 'emotional talking' for them. Hence it is important to think about the role of neurodiversity when assessing a CYP presenting with BDS.

One of the most helpful things you can do if you are beginning to wonder if a significant component of the CYP's presentation contains BDS, is to plot their symptoms over time, and relate these to school year, time point in the school year, onset of puberty and menarche and any other major events in the family's life e.g. divorce and separation, parental ill health, job loss or threat of redundancy or death, grandparental ill health or death, injury or illness in the child, peer difficulties or trauma. Note also any social care involvement, which may relate to psychosocial stressors in the whole family unit.

As well as a chronology, a formulation, considering the '4 Ps' for a presentation can be a really helpful exercise, for example highlighting the number of systemic factors that are perpetuating or holding the child in their current situation. To aid with this we have added a blank formulation in Appendix 6.

Once you've done this, liaise directly (preferably in person) with any other clinicians involved, both current and past, and ask them what they felt was going on at the time (don't just read clinic letters; they will tell you little about the real context). This tends to be far more time effective in the long run and allows for better communication and a shared understanding. Also request that colleagues document their views (e.g. in secure email or letter correspondence) if you feel the nature of the discussion and its implication warrants this.

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16 Hadji-Michael et al (2019) Alexithymia in children with MUS

17 Fiertag et al (2019) BDS and related disorders in CYP

Table 6: Predisposing and precipitating factors that may suggest and contribute to a psychological basis for BDS.

Child factors	Family factors
- Are **social stressors** present? e.g. bullying or strained family situation - Is the CYP **sensitive** to psychological events and social changes? - Does the CYP have a **perfectionist attitude**, leading them to work very hard at school and currently feel undue pressure? e.g. exams - Does the CYP appear **unable** to openly **react** to or **communicate** their distress? Consider both environmental and genetic factors such as emotional neglect, a learning disability and autism. - Does **exacerbation** of the symptoms coincide with **stressful situations** e.g. Sunday night/ Monday mornings or a parental argument? (Ask the parent to keep a diary). - Is there a **history or evidence** of physical, sexual or emotional **abuse**? - Does the CYP have behaviours that may be challenging family dynamics and affecting parental relationships? - Are there symptoms suggestive of **significant psychological distress**, previous **trauma** and/or a possible **underlying psychiatric disorder**? - Has there previously been an **illness event** that might have led to BDS	- Is there a **family member** who suffers from **BDS**? - Is there a **family member** with **psychiatric disorder** (especially maternal depression)? - Is there evidence of **emotional rejection** in the family? - Is there evidence that a **family member** uses the CYP to **fulfil their emotional needs** excessively?[‡‡] - Is there **family adversity**? e.g. divorce, parental discord or bereavement. - Are family members **overly critical** towards the CYP or is there evidence of **taunting and belittlement**? - Are family members intrusively overprotective? - Is there the use of **threats of violence**, **abandonment** or **excessive guilt** as a form of discipline? - Does the family impose **inappropriate responsibilities or expectations** on the CYP for their level of maturity? - Is there lack of parental authority and inconsistent discipline? - Has an in-depth and holistic **family history** (including potential trauma) been sufficiently obtained for **three** generations?

[‡‡] May be suggestive of possible factitious or induced illness. See table 8 for more details.

EXPLORING PSYCHOSOCIAL FACTORS - USING 'THE BATHE TOOL'.

Exploring psychosocial factors in sufficient detail can prove challenging in a busy clinic setting, so you may want to explore using 'the BATHE tool'.

It provides a framework for rapidly exploring psychosocial factors that may be exacerbating the CYP's BDS. For some (particularly below the age of 11 or with learning difficulties), the tool may not be suitable, or the questions may need to be adapted to be developmentally (age and stage) appropriate. However, it provides a basic structure to explore the psychosocial component of the CYP's presentation.

Table 7: BATHE Technique.(18) Screening tool for assessing mental health

B: Background	What is going on in your life?
A: Affect	How do you feel about it?
T: Trouble	What troubles you the most about the situation?
H: Handle	What helps you handle that?
E: Empathy	This is a tough situation to be in. Your reaction makes sense to me.

SAFEGUARDING ISSUES AND POSSIBLE FABRICATED OR INDUCED ILLNESS (FII)

For some CYP who present with BDS, fabricated or induced illness must be considered. Your index of suspicion should be higher for FII when the parent is the main complainant about the CYP's symptoms, speaks for the child, persists in requesting more investigations than you and other senior colleagues feel are justified given the physical examination and investigation results, is seeking a diagnosis that is inconsistent with what you observe in the CYP's history, examination and investigations, and/or does not accept a psychological approach to symptom management (after all, even in organic conditions, symptom management may require adapted behaviours and approaches in the CYPF, and sometimes explicit psychological treatments).

The RCPCH endorsed guideline on the 'Fabricated or induced illness by carers (FII)', now better known as Perplexing Symptoms, is a useful resource for more information. It can be found here: Perplexing Presentations (PP)/Fabricated or Induced Illness (FII) in children. [***] The investigation and management of FII sits outside of the scope of this guideline.

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18 Leiberman and Marian (1999) The BATHE Method

[***] childprotection.rcpch.ac.uk/resources/perplexing-presentations-and-fii/

Some parents can develop, for various reasons, excessive anxiety about their child’s health. It is important to distinguish this from FII since they may present with repeated requests for further investigations and/or treatments to alleviate their own anxiety, rather than consciously using their child to access help, support and attention for themselves. They may have their own history of health anxiety and they can be best supported by discussing this separately from their child and agreeing a way forward for their own difficulties.

TAKE AWAY MESSAGES FROM STEPS 3 AND 4

On receipt of the referral to secondary care, many doctors find it difficult to shift their focus from investigation to management and symptom control.

The four key questions that are important to answer at this stage are:

1) Are there any red flags associated with the presenting symptoms which are suggestive of an underlying organic pathology?

2) Could the CYP have some kind of underlying psychiatric disorder?

3) Are there any factors in the school, home or peer group which could be contributing to the CYP’s presentation?

4) Is this CYP at risk of harm?

If these avenues have been explored sufficiently by the MDT, then you should instead shift your focus to symptom control and on-going psychosocial explorations. We present these 4 areas – physical, psychiatric, social and environmental and safeguarding - as separate points to consider, but we want to emphasise the interconnected nature of these factors in both the system that is the child within their family and social network, and in the presentation of the child to services. We encourage clinicians to take a holistic approach to these presentations and consider these factors both separately and in unison.

STEP 5: THE MANAGEMENT OF BDS AND RETAINING A LONGER-TERM CONNECTION WITH THE PATIENT

Once medical investigations are definitively completed - and there must be a firm line drawn at this stage - the focus can shift to understanding the CYP's symptoms in a different way, with the emphasis on investigations changing to that of symptom management.

It is important not to allow the CYP and their family to feel abandoned at this stage. Their symptoms are still present, feel just as bad and must be respected with just as much serious attention as they were during the investigatory stages.

Appendix 7 is a leaflet that can be given to CYPF once the presence of BDS has been identified.

Create a simple management plan with the CYP and their family to help them manage the symptoms effectively. Table 8 outlines some examples of what management to offer.

With the exclusion of pathology and a simple management plan in place, it is appropriate to transfer the CYP's care back to the GP for on-going symptom management and review, ideally remaining in the background yourself. Best is a phone call to the involved GP, but if not, your letter should note the absence of 'Red Flags', exclusion of relevant pathology and **that no further investigation is currently indicated**.

However, 'Red Flags' can develop at any time (see tables 1-5 for examples). Therefore, emphasising to the CYP and family, and mentioning in your GP letter that the CYP can be re-referred in the future should further investigation be warranted is an important part of your handover management. In addition, it can be helpful to caution about re-emergence of symptoms and emphasise your willingness to get involved again should this occur.

Communication Tips

Don't focus on giving a **diagnosis**

Do focus on **symptom** management

Empathise with the situation and the frustrations the CYP and their family are feeling, especially if no cause is identified

Empower the CYP and family by involving them in creating the initial management plan

Use **word scripts** for difficult conversations - Appendix 2

Don't abandon the CYP and their/family with their symptoms after medical diagnoses have been **excluded**.

Evidence your on-going concern by the co-creation of the care plan and carefully **negotiating step down to primary care**. Mention future review as a possibility

Appendix 5 is a letter template that can be sent to the GP.

As well as communicating with the GP, it is important to update school and social services (if previously involved). Signpost them to online educational resources and advice that may help educate and support the CYP, as well as those working with them (See **Appendix 4** for an example list of support services).

DISEASE COURSE FOR BDS

There are three **possible trajectories** for CYP who present with BDS.

1) **The spontaneous resolution of symptoms:** For a significant number of CYP, their symptoms will resolve spontaneously over time. Table 12 (in Appendix 1) outlines the prognosis of symptoms depending on the system involved.(19)

2) **The persistence of symptoms with adequate symptom control**: For a number of CYP, symptoms may persist but at a level where they do not impair function for a significant amount of the time. Reassurance and/ or simple management strategies (instead of diagnosis and cure) may be all that is required to cope with their symptoms and to ensure that a healthy quality of life is maintained.

3) **The persistence of symptoms with inadequate symptom control:** For around 1% of CYP, symptoms will become chronic and poorly controlled. It is this group that are at the greatest risk of medical child abuse and are the highest health service users within the BDS group. They need careful management and support. For some, a referral for psychological interventions or to psychiatric services may be appropriate. For further information, see 'Step 7: Involving experts when necessary'.

Only time will determine which trajectory a CYP with BDS will follow, and unless one person holds an overarching view of the CYP's care (typically a nominated paediatric consultant), progress may be poorly judged and symptoms inadequately, rather than adequately, controlled.

Consider the management of BDS as a cycle. Symptoms can change over time and red flags may develop on the background of chronic symptoms. CYP who present with BDS may go on to develop a concurrent organic illness, so reinvestigation may be necessary at a later date. CYP also want to feel listened to and understood, and even CYP who are successfully managing their symptoms should have regular planned reviews to ensure an underlying illness is not being missed. Depending on the level of symptomatology, a single appointed lead GP or paediatrician is therefore best placed to be the long-term reviewing doctor for a CYP with BDS.

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19 Rosendal et al (2017) MUS in primary care

EXPLORING, UNDERSTANDING AND APPRECIATING A CYP AND THEIR FAMILY'S CONCERNS

Family anxiety surrounding a CYP's bodily distress symptoms is natural and should be acknowledged and legitimised. It is very possible that the parent or carers' anxiety will persist despite your reassurance and exclusion of underlying organic pathology. This is a normal reaction in any concerned parents/carers. If this anxiety is persistent and significant, this may be a perpetuating factor in the child's distress, and therefore the parents themselves may benefit from support with their anxiety. This is why exploring and understanding the impact the symptoms have on the CYP and their family should be considered a routine part of your management.

Table 10 outlines family factors that can increase the chances that bodily distress symptoms will persist rather than resolve spontaneously or become adequately managed. If such factors are present, and symptoms remain debilitating despite an adequate trial of management strategies, a referral for family psychological support i.e. family therapy should be considered. This setting offers the opportunity to think about symptoms in a different way i.e. to re-frame them in the family mind-set, the aim being to better understand what the symptoms are achieving (e.g. protecting the CYP from aversive experiences like a return to school, growing up, becoming more independent etc) and to help the family and CYP shift the focus from illness onto rehabilitation and symptom control.

Table 11 outlines the various psychological support services. Unfortunately, the demand for family therapy often exceeds the availability. Therefore, responsibility lies with all healthcare professionals involved with the CYP to approach and explore unhelpful family dynamics, including predisposing, precipitating and perpetuating factors that may hinder recovery (see Tables 6 and 11).

EFFECTIVE COMMUNICATION

Poor communication risks undermining the therapeutic relationship and may lead to the CYP and their family losing trust in you and the medical profession. This can alienate the CYP, exacerbate their symptoms and lead to recurrent presentations to primary and secondary care in search of help, a diagnosis and a cure. By using the communication tips provided in every section of the guide, along with word scripts for difficult conversations (Appendix 2), you should minimise the likelihood of your communications triggering hostility and defensiveness in the CYP and their family. Language is important and how the idea of BDS is communicated can have lasting implications – be mindful of your verbal and non-verbal communication in the room – convey warmth and empathy but also be firm and containing of anxieties. It may be necessary to move between the two approaches several times during a consultation. We encourage the use of the MDT for assessment and formulation where multiple perspectives are always helpful, but very often the communication about outcomes and next steps is best given from a since perspective to limit confusion.

Communication Tips – from a CYP/family perspective

1) Please don't make us feel **guilty** for being an in-patient, especially when you haven't shared your suspicions about BDS with us. My child's pain and inability to walk was as **real** as any other medically understood child's symptoms.

2) Please be **honest** from the outset - explain that BDS **doesn't** mean that you don't actually know what's wrong with my child.

3) Please **don't** tell me that my child is **making it all up**, or that it is **all in his head** - this leads me to question my own sanity and then not be fit to support my child in their time of crisis.

4) Please spend time listening to the **whole history**, diagnoses offered, parent and CYP thoughts as well as the emotional state of the CYP and family.

5) Explain to me that the pain my child is feeling, despite not having a medical explanation, is still a **genuine** pain that hurts like any other pain.

6) Don't tell me that there is **nothing** more you can do for my child and send me home with a child, in a worse physical condition than when we arrived and with the prospect of very little outpatient support.

7) Make sure that you **communicate** between yourselves so that I don't get 3 or 4 different messages from different doctors, specialists or departments and so that I don't have to retell the history hundreds of times.

GUIDANCE FOR MANAGEMENT – TABLES

Appendix 3 also offers a flow diagram for assessment, diagnosis, management and referrals. These management strategies should be trialled for up to 6 months.

Table 8: Management strategies (should be trialled for up to six months)

System	Simple management advice
Palpations, shortness of breath	Relaxation techniques – see Appendix 4 for resources
Back/limb pain	Heat packs, physiotherapy, regular exercise NSAIDS, diclofenac patch, muscle relaxants Relaxation and distraction techniques
Fatigue	Gradual increase in activity i.e. grading and pacing advice (after establishing a baseline) Sleep hygiene advice. NICE guidelines on Chronic Fatigue Syndrome[†††]
Abdominal pain	Heat packs, dietary modification, simple analgesia, antispasmodics, peppermint oil IBS patient leaflet[‡‡‡] Stress management, relaxation and distraction techniques
Headache	Avoid triggers e.g. lack of sleep/excessive TV use. Simple analgesia: paracetamol, ibuprofen, relaxation and distraction techniques Sleep hygiene advice. Exercise. Chronic tension headache leaflet[§§§]
Limb weakness	Consider amitriptyline/gabapentin. Graded exercise. Physiotherapy, OT
Dysuria	Adequate fluid intake, avoidance of caffeine and alcohol. Overactive bladder syndrome patient leaflet[****]

[†††] www.nice.org.uk/guidance/cg53

[‡‡‡] patient.info/digestive-health/irritable-bowel-syndrome-leaflet

[§§§] patient.info/brain-nerves/headache-leaflet/chronic-tension-headache

[****] patient.info/womens-health/lower-urinary-tract-symptoms-in-women-luts/overactive-bladder-syndrome-oab

Table 9: Further management strategies for severe symptoms.

Pain clinic

Fatigue clinic

Relaxation techniques

Psychological therapies e.g. cognitive behavioural therapy

Graded Exercise Therapy

Self-management strategies: see Appendix 4

Psychological therapy e.g. family therapy if perpetuating factors identified

Support groups: see Appendix 4

Table 10: Advice for exploring situations where symptoms fail to resolve

Family factors that may contribute to persistence of BDS in a CYP	Examples of systemic questioning allowing exploration of the family set up
- Are any members of the family **particularly distressed** about the CYP's symptoms and why? - Does this focus unnecessary attention on the symptoms? - Does the family **always** have a **medical approach** to illness rather than a psychological one? - Is there evidence of **low 'emotional literacy'** in the family? (i.e. a difficulty talking about or understanding each others' states of mind) - Is there evidence of **high expressed emotion** in the family? - Are family members **intrusively overprotective**? Is the 'sick role' inadvertently encouraged?	- What are the family 'beliefs' about the illness? - When did it start? - What was 'going on' at the time? - How severe is it? Will it get better? - What would need to happen for it to get better? - Are there differences in these beliefs-why might they be important? - Who is most worried and why? - What 'function' does the illness serve? - What would change in the family if it resolved? - And by extension, what is the illness maintaining? - What is not being thought about?

Table 11: Different psychological support services

Counselling of CYP or parent/carer	Sessions are non-directive, unstructured, and supportive and aim to help the CYP or parent (as adult patient) cope with difficulties not severe enough to require specialist psychological interventions Parental/carer counselling focuses on enhancing parental coping by allowing them to work through problems and find their own solutions
Family Therapy	Sessions involve various combinations of the entire household, as well as non-resident grandparents or other involved relatives. Work aims to detect and address dysfunctional family relationships that may be inadvertently contributing to persistence of the CYP's BDS
Cognitive Therapy	Sessions and homework are used to uncover and explore unhelpful thinking styles which may be driving negative feelings, beliefs about the self and associated behaviours
Behavioural therapy	Sessions focus on eradicating specific behaviours that are felt to be both maladaptive and detrimental to a CYP's quality of life
Psychodynamic Psychotherapy	Sessions tend to be more frequent e.g. at least once weekly and aim to explore in a more in-depth manner unconscious conflicts that may be driving the BDS
Parenting Groups	Sessions known as 'Parent Training' tend to be highly structured and deliver a course aimed at enhancing parenting receptivity to their CYP's positives, as well as building greater effectiveness in their parenting approaches to unhelpful behaviours Parent support groups – see counselling

STEP 6: MANAGING YOUR, AS WELL AS OTHER STAFF MEMBERS', FEELINGS ABOUT THIS TYPE OF WORK

Work with CYP with BDS can stir up strong feelings in those caring for them. Some physical healthcare staff can really struggle to accept that these bodily distress symptoms are 'real' and can inadvertently make CYP feel like frauds (especially as they lie in a hospital bed / attend an outpatient clinic alongside another CYP with diagnosed physical illness). Such feelings, even if unexpressed, can begin to feel frankly aggressive towards the CYP and their family.

Equally, some staff can experience overwhelming, and at times almost disabling, feelings of failure and inadequacy. Healthcare is often about making our patients 'better' and everyone struggles when this is not happening. If you can remind yourself and your colleagues that it's precisely not about 'making' the CYP better, but about sticking with them as their body/mind dis-ease eases and they start to lose their symptoms/learn how to adapt to them and progress nonetheless.

Whoever is acting as lead doctor on the case will have to hold the hope / positive outlook. If this is you, you will need to remind everyone, staff, as well as the CYP and family, that the mainstay of all your approaches is to show the body that we mean to slowly, slowly get back to 'business as usual' i.e. that you and the team will be encouraging the CYP's body to function, as much as possible, and not necessarily all at once, within a daily schedule that is about as ordinary an existence as possible for someone of their age. This expectation needs to stay in place throughout recovery/into the chronic symptom management phase, and it can sometimes be one of the most difficult things that you will have to hold on to.

Communication Tips

- Don't **force a psychological explanation** on the CYP and family. Allow them time to make the connection in their own time

- Remain **non-judgmental**

- **Reiterate and normalise** the **impact that stress** can have on symptoms e.g. muscles overuse/tension causing back pain

- **Acknowledge** that the CYP is **genuinely experiencing the symptoms** and it is important to support them emotionally during this time

- Use **word scripts** for difficult conversations if you struggle to know how to talk about BDS

STEP 7: INVOLVING EXPERTS WHEN NECESSARY

Involving experts in the right way and at the right time is essential. A ‘gold standard’ approach to the management of BDS involves collaborative care from the start. A ‘stepped approach’ should be taken with different levels of intervention. The CYP’s progression will depend on how well they respond to each level of intervention.

7A BASIC INTERVENTION

All children with a presentation that has a component of BDS should be seen by a practitioner who understands BDS, can introduce and explain the possibility *at the first consultation,* and provide basic interventions. Senior paediatric clinicians should be involved from an early stage to facilitate this.

It’s understandable for families to ask for additional professional involvement. If seeking a second opinion – this can be done as a joint appointment with another clinician in the department to deliver a unified message – no further investigations/specialist referrals unless the clinical picture changes.

7B JOINT REVIEW/ MENTAL HEALTH CONSULTATION

At this point, basic interventions have been tried. Local mental health specialists should be involved. This may be at the level of consultation, or ideally via a joint review with paediatric and mental health clinicians. Screening for specific mental health conditions should occur at this stage.

7C FURTHER SPECIALIST ASSESSMENT

Further assessment and intervention by mental health specialists.

Importantly, these stages are not fixed, or time-bound. If concerns are very high at initial assessment, then rapid escalation and specialist support may be necessary. A delay in appropriate management and support may cause the CYP to miss large amounts of education and social interaction, both of which are vital for healthy development.

Appendix 3 gives an outline of when a CYP who presents with BDS should be referred to psychological or psychiatric services. It follows the general rule that a paediatric psychology or paediatric liaison referral is preferable when organic illness is under investigation or has been identified. A CAMHS referral is prioritised when an organic cause has been sufficiently excluded.

When discussing the wish to involve mental health colleagues in the CYP’s care, it is important that you continue to acknowledge the serious impact of their symptoms and your own need for help in working out how best to help them. Families are likely to be understandably defensive if the decision to refer comes without warning or a pre-emptive discussion about the important interplay between mind and body. CYP and family engagement is generally better if a **joint approach** is taken rather than care being transferred from physical to mental health services. You should aim to remain involved with cases even after mental health intervention has begun for several reasons:

1) To avoid communicating to families and young people that the symptoms are no longer a concern to you / physical health.

2) To remain accessible for overlooked or emergent pathology.

3) For ease of access to further physical investigations and therapy e.g. physio.

However, despite their known efficacy, many hospitals do not have an in-house mental health liaison service and at best may have only one nurse to cover the entire inpatient and outpatient department during office hours. Because of this, the threshold for specialist service involvement and capacity for collaborative care may be limited.

In order to achieve the 'stepped care' model in all trusts:

The case needs to be made by **senior clinicians** from both physical and mental health for the **benefits of effective liaison services**. In certain cases, support may also need to be commissioned from mental health trusts as well.

There should be **joint leadership** at a local level by **child health and mental health**, incorporating training of staff and agreement between both about protocols for joint work and referrals.

There should be **minimisation of organisational barriers** to joint work, including ready access to consultation, training and joint appointments. Co-location is also encouraged where possible.

The RCPCH recommends that **all** paediatric hospital departments have a **senior Clinical Lead** for Children and Young People's Mental Health.

A FINAL NOTE

Working with BDS can be challenging, with the navigation through various diagnostic investigations to the acceptance of symptom control (not cure) being difficult for doctors and patients alike.

At worst, diagnoses can be missed, and/or significant medical child abuse occurs. In particular, poor communication risks the destruction of the therapeutic relationship and may lead to the CYP and their family losing trust in the medical profession. Furthermore, this can exacerbate the CYP's symptoms and lead to recurrent presentations to primary and secondary care in search of help, a diagnosis, and a cure.

By keeping an open mind, maintaining a degree of unconditional positive regard and seeking support from this guide and other professionals, you can help prevent destruction of the therapeutic relationship, minimise the risks of medical child abuse and lessen the economic burden of BDS. You can also increase your own confidence and satisfaction with work that you have previously found challenging and a significant source of stress.

SUMMARY AND ‘HOW TO’

1) Step 1 – opening your mind to the possibility of BDS
    a. Consider the role of bodily distress in new presenting patients early – reflect on how you are using investigations – who is this for?
2) Step 2 - beginning the conversation
    a. When ordering new investigations, prepare the family for what a ‘normal’ test will mean (and what it will not mean)
    b. Talk with patients and their families about the link between our emotional and physical states – this is normal for everyone in all conditions
    c. Convey to patients that their mental and physical health is closely related and we care about both – thinking about bodily distress isn’t dismissing their experience or sending them off to another specialty
3) Step 3 – avoiding under- and over-investigating
    a. Consider and communicate a finite but relevant set of investigations to complete and then stop – observing for development of red flag symptoms, record their absence to evidence the end of necessary investigations
    b. Illness events can be a trigger for BDS
    c. Functional overlay is common in those with diagnosed ongoing physical health conditions
    d. Assess for psychiatric comorbidity - wherever possible, working closely alongside paediatric liaison, psychology of CAMHS colleagues to identify underlying psychiatric illness
4) Step 4 – chronology, psychological and wider social factors
    a. Timelines, family, social, and developmental histories will give important clues pointing towards BDS (or away from it) – liaising directly with clinicians previously involved in care will always be best for clear information about the context of previous investigations
    b. Consider psychological factors in the child and wider factors in the family that might suggest a basis for BDS – use the BATHE tool to explore these, these factors increase the chances that symptoms will persist
    c. Consider fabricated or induced illness and other relevant safeguarding concerns
5) Step 5 – long-term management
    a. Once a diagnosis of BDS is established, move away from diagnostic focus and onto symptom management

    b. BDS are likely to spontaneously resolve, or less commonly require ongoing symptom management, and only rarely become chronic and poorly-managed – these patients benefit from a lead clinician spearheading care
    c. Acknowledge the role of parental stress in the presentation – consider what support services you can recommend to the family
    d. Your communication with the family is key
    e. There are many self-management strategies you can recommend, or signposting to other organisations, before a referral on to other departments is needed

6) Step 6 – managing ours and our colleagues stress
    a. Managing BDS can be difficult, but remaining non-judgemental, normalising BDS and acknowledging symptoms as real without a physical cause can set a helpful framework for long-term engagement
    b. Managing BDS is difficult for us as well as families – do seek appropriate supervision if you are struggling
7) Step 7 – referring on
    a. Introduce the idea of BDS early in consultation
    b. Second opinions are best used as joint appointments with clinicians within the same department
    c. Joint reviews with mental health teams can be helpful
    d. If there are identified likely psychiatric comorbidities, then do refer into secondary services for further assessment

A CASE STUDY OF BDS

BACKGROUND

- Age 13 at presentation
- White British female
- Two parent family
- Older of two sisters (younger sibling 10)
- Attending non-selective girls state secondary school, Year 8/9 cusp
- Home counties residents, owner occupiers
- Both parents' professionals, mother not currently employed because of child's care needs

PRESENTING COMPLAINT

7 – 11 July

- Admission to teaching hospital from the local eating disorders clinic with sub-acute deterioration
- 'Struggling to walk 200m, lack of balance and dragging her left foot, reduced power in all four limbs.'
- Paediatrician noted fixed flexion deformity
- Home via the local district general, after agreement that symptoms could be adequately managed at home
- Diagnosis by physios: chronic fatigue with functional overlay

3 August

- Admitted with acute deterioration in symptoms to teaching hospital, direct from a family holiday in Spain
- During the holiday, she had undergone a rapid decline, with widespread weakness and extensive immobility
- Unable to feed self or meet own basic care needs
- Mother wanted to take her to a Spanish hospital but father insisted they wait to consult doctors when they got back to the UK

HISTORY OF PRESENTING COMPLAINT AND TIMELINE

- January of Year 4, started feeling tired a few days before school term started
- Year 4 "a write off". 90% attendance despite tiredness and abdominal pain
- July of Year 4 coeliac disease diagnosed. Symptoms resolved with diet

- September Year 5 all fine. Year 5 and 6 no issues
- October of Year 7, abdominal pains “within weeks” of starting at secondary school
- Stopped PE by end of first half term because of “acid regurgitation when she ran”
- January of Year 7, mother asks GP to refer for autism assessment (goes on waiting list)
- February of Year 7, now on a reduced timetable at school, with increasing time away from peers in student support
- May of Year 7, five-day admission to local DGH refusing to eat. Reporting feeling full after ever decreasing amounts of food. Sent home on ENSURE with referral to CAMHS. Seen July and referred to specialist inpatient unit within a paediatric setting
- September of Year 8, specialist inpatient unit diagnoses atypical anorexia “it didn’t seem off piste” said mother of this diagnosis and referred to the local eating disorders service. “I didn’t feel I was in the same boat as the other parents” (in the ED service)
- Year 9 starts an intensive day programme (including education) which runs all academic year
- During the summer term of Year 9, during increasing periods of school reintegration, posture deteriorates and complaints of tiredness increase. Repeated visits to GP are met with the response “nothing’s wrong”. Mother experiences feelings of “utter helplessness”. Intensive therapist queries conversion disorder, but X-rays raise concern about possible previous scurvy

OVERVIEW OF INVESTIGATIONS

Endoscopies

- June 2011: OGD - consistent with coeliac disease
- May 2014: OGD and a colonoscopy - unremarkable
- July 2014: Capsule Endoscopy - unremarkable

Ultrasound

- April 2014: Abdominal ultrasound- unremarkable

Imaging

- July 2014: Abdominal MRI scan - unremarkable
- July 2015: Spinal X-Ray - unremarkable
- August 2015: Head and spinal MRI - unremarkable
- August 2015: Bilateral knee X-ray - Flexion deformity / slightly osteopenic/no effusions

Blood Tests

<u>May 2014</u> - Faecal calprotectin - 476 (<51), June 2014 - 840, September 2014 - 281

<u>August 2015</u>

- SM antibodies - negative
- Mitochondrial antibodies - negative
- Gastric parietal cell antibodies - negative

- Antinuclear antibodies - negative
- Anti-streptolysin 0 - negative
- EBV DNA - negative
- Rheumatoid factor - 7 (<9)

September 2015

- ESR - 35 (<15)

Treatment involved parallel working between nursing on the ward (in a manner that did not ‘indulge’ or give excess attention to the symptoms), week day physical therapies, week day education in the hospital school (a place to feel competent and not sick), psychological work with the family, behavioural work (exposure mainly) with the young person, regular appearances by the paediatric consultant alongside the paediatric liaison consultant (to embody concretely the joining of mind and body) and regular MDT work / communication to ensure that everyone was working in unison and pulling in the same direction (even those who struggled to accept the nature of the presentation, and understand that it was not fabricated or attention-seeking).

TIMELINE OF TREATMENT AND RECOVERY

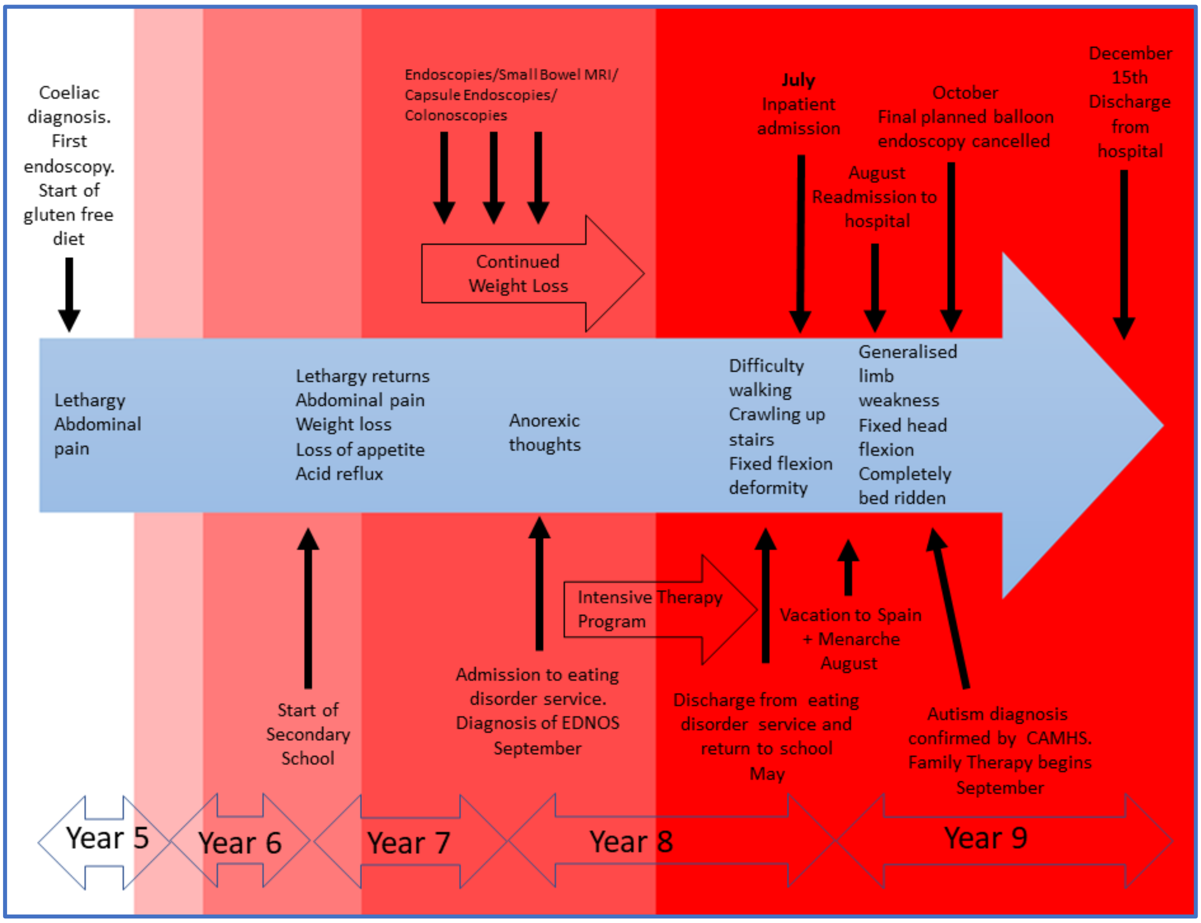

Figure 1 - Timeline of development of BDS

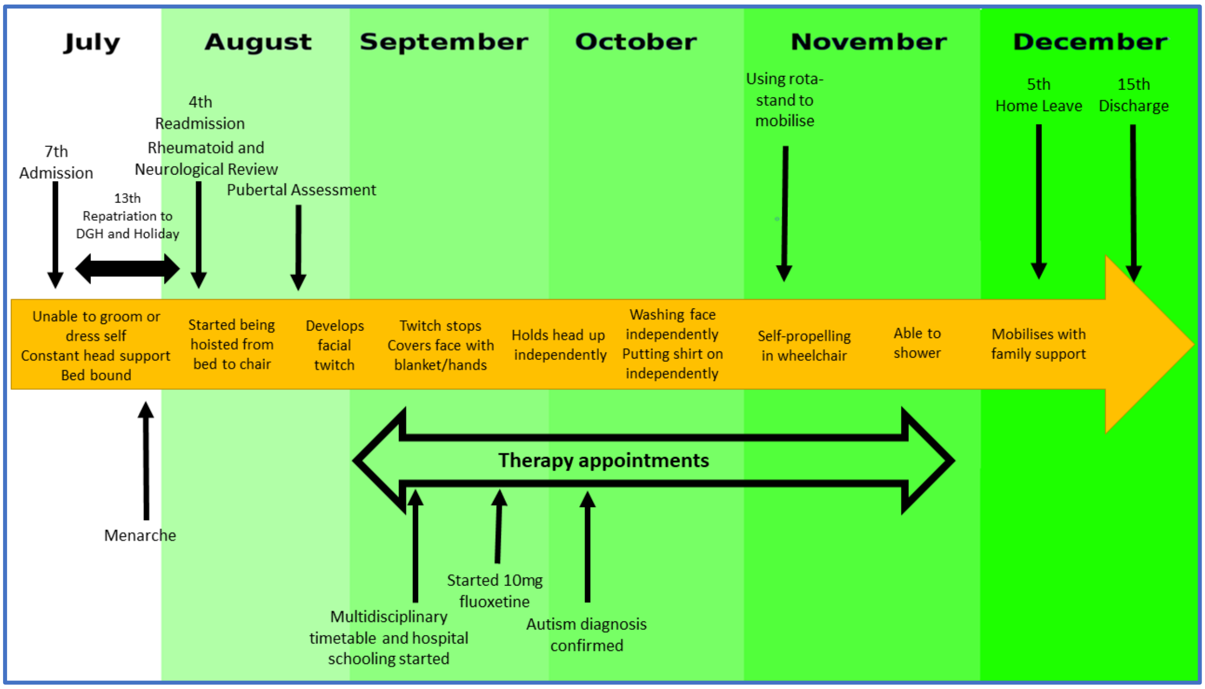

Figure 2 - Timeline of treatment and recovery for patient

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APPENDICES

APPENDIX 1 - PROGNOSIS

Table 12: Prognosis of BDS(8)

System	Frequent BDS presentations	Recovery after 12 months (%)
Cardiology/ Respiratory	SOB, palpitations, chest pain	47%
Gastroenterology	Vomiting, abdominal pain, dysphagia, nausea, bloating, diarrhoea	42%
Musculoskeletal/ Rheumatological	Back pain, joint pain, pain in arms/legs	55%
Neurology	Headache, dizziness, LOC, amnesia, visual disturbance, tinnitus, paralysis, muscle weakness, PNES	38%
Gynaecology/ Urogenital	Dysuria, dyspareunia, dysmenorrhoea, irregular menstruation, menorrhagia	34%

APPENDIX 2 – CONSULTATION SCRIPTS

The **Textbook of Adolescent Medicine** suggests a dialogue along the lines of;

‘It is clear that you have been experiencing some difficult symptoms for quite some time. Our aim is to identify what is causing these symptoms. As you have had these symptoms for quite some time now it is unlikely they will go away very quickly so we need to put together a plan that reduces your symptoms so they don’t interfere with your life so much. ‘

‘We know that people who have to deal with these symptoms for a long period often start to feel down, do you think this is the case with you?’

‘We also know that if you are feeling low or have emotional stress in your life that this stress can make your symptoms feel worse, so, it is important that we consider your emotional health as well as your physical health to try and improve things for you as much as possible’ “Some people find speaking to a member of our mental health team helpful in this situation’.

Colleague Suggestions

Colleagues have suggested the phrase ‘Yes, I can arrange this scan/test, but I think it is likely to be normal. What shall we do then, as your child will still have these troublesome symptoms?’ as a helpful way to open dialogue around normal investigations with persistent symptoms.

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8 Rosendal et al. (2007) Classification of MUS

Goal Setting and Restoration of Function

Moving the conversation towards positive goals after dealing with negative results can be a more productive end to consultations

Preparation for consultation **-** Develop summary of problems and potential treatment plans prior to consultation

Educate the patient

- Evaluate the patient's understanding & illness beliefs
- Discuss MUS and how problems associated with this diagnosis apply to the patient|
- Describe treatment options and the associated risks and benefits
- Describe the prognosis of the illness

Treat anxiety, depression and any other mental health problems

- Medication
- CBT Therapy or counselling
- Referral to specialists

Collaborate with the patient and determine their preferences

- Determine the patient's goals for recovery
- Determine the patient's opinion on priority of problems and urgency for treatment
- Determine the patient's opinion on the recommended actions or options
- Determine the patient's motivation towards, and identify barriers to, treatment
- Obtain the patient's consent to the plan

Goal-setting

- Restoration of function is the main goal of treatment
- Negotiate brief, measurable and achievable goals with the patient
- Only 2/3 goals should be made at each consultation
- Goals should be reviewed and updated at each consultation

Empower the patient for self-management

- Move the responsibility of patient improvement to the patient
- Encourage a change in lifestyle, including exercise, diet & stress reduction

Implement the action plan

- Coordinate treatment /action plan activities
- Establish a referral and interdisciplinary team approach, if indicated

Reframing – Negotiating a new model of understanding after negative results

- Physiological imbalance – often bowel symptoms can be caused by imbalances in the way the intestines work – pressure build ups cause pain and rapid transit diarrhoea

- Reaction to stress and strain/nervousness – I sometimes see such reactions in stressed people. Do you think this could be the problem in your case?

- Depression lowers pain threshold “we are more sensitive when depressed” – when we are depressed the pain becomes more intense, because you are more sensitive – could this be the case for you?

- Muscular tension in anxiety and nervousness – stress and emotional strain can result in muscular tension. I have seen this in many patients. I wonder if there could be such a link for you?

- Demonstrations

    - Practical (hyperventilation, muscular tension) – if you go shopping and carry home heavy bags then your arms may start hurting. Likewise, a little tension in your muscles over a long time will cause pain. What do you think about this?

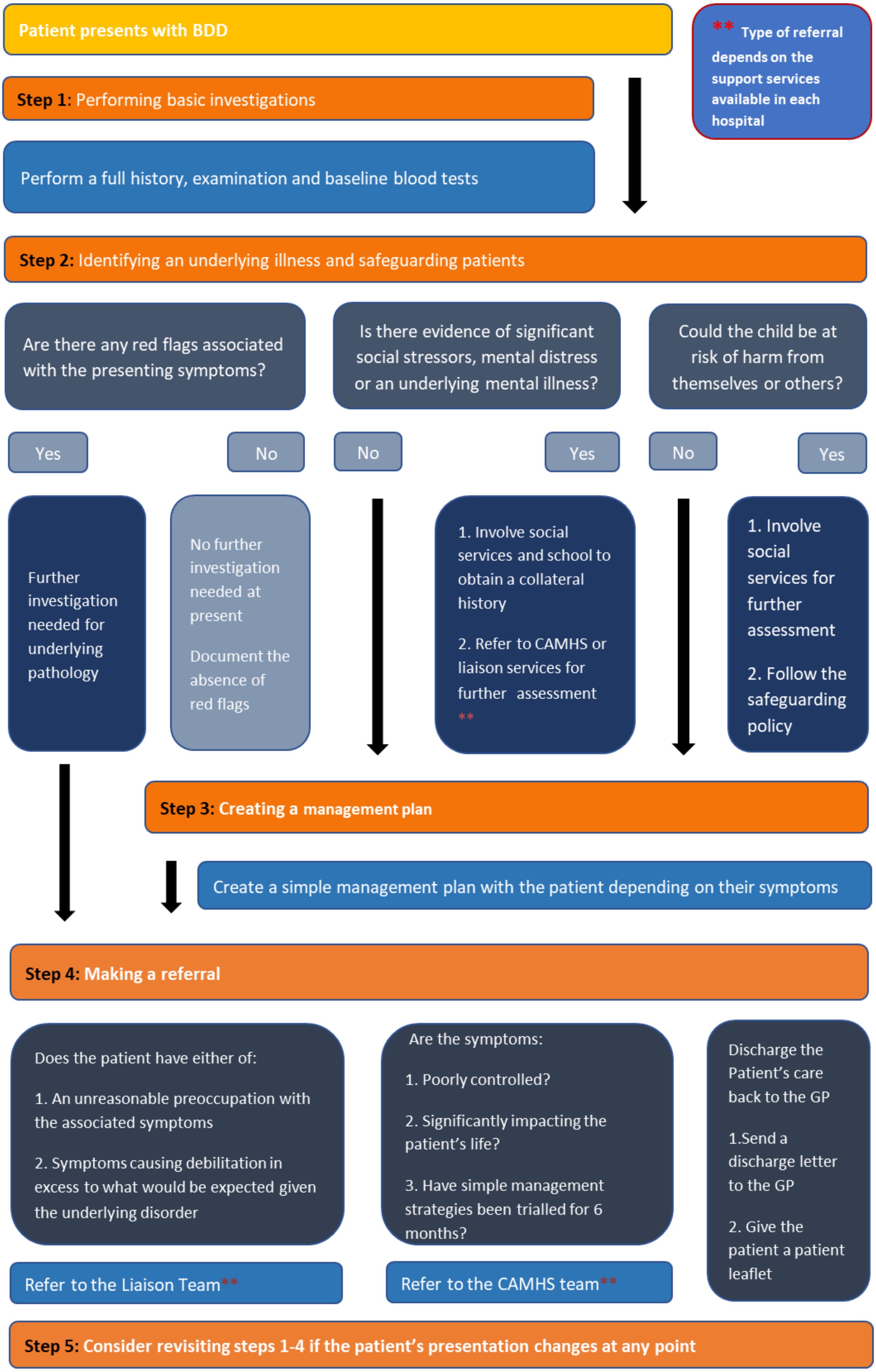
    - ‘Here and now’ (nervous about consultation – only use if clearly symptoms at that moment) – I can see you feel bad when we discuss this. How does it feel in your **body part** right now?

- Normalising explanation (either)

    - Temporary imbalance in your system that will right itself in time, this could be related to hormones, nerves, muscles. The more you think about/touch the affected area, the worse it feels

    - Give explanation relating physical symptom to psychosocial problems of lifestyle because of link in time or physiology. E.g. stress at home causes muscles in your body such as your back to tense, and muscles held tight for long periods ache.

APPENDIX 3 – FLOW CHART FOR ASSESSMENT AND MANAGEMENT



Patient presents with BDD

** Type of referral depends on the support services available in each hospital

Step 1: Performing basic investigations

Perform a full history, examination and baseline blood tests

Step 2: Identifying an underlying illness and safeguarding patients

Are there any red flags associated with the presenting symptoms?

Yes: Further investigation needed for underlying pathology

No: No further investigation needed at present

Document the absence of red flags

Is there evidence of significant social stressors, mental distress or an underlying mental illness?

No

Yes:

1. Involve social services and school to obtain a collateral history
2. Refer to CAMHS or liaison services for further assessment **

Could the child be at risk of harm from themselves or others?

No

Yes:

1. Involve social services for further assessment
2. Follow the safeguarding policy

Step 3: **Creating a management plan**

Create a simple management plan with the patient depending on their symptoms

Step 4: **Making a referral**

Does the patient have either of:

1. An unreasonable preoccupation with the associated symptoms
2. Symptoms causing debilitation in excess to what would be expected given the underlying disorder

Refer to the Liaison Team**

Are the symptoms:

1. Poorly controlled?
2. Significantly impacting the patient's life?
3. Have simple management strategies been trialled for 6 months?

Refer to the CAMHS team**

Discharge the Patient's care back to the GP

1. Send a discharge letter to the GP
2. Give the patient a patient leaflet

Step 5: **Consider revisiting steps 1-4 if the patient's presentation changes at any point**

APPENDIX 4 - RESOURCES

SUPPORTIVE RESOURCES

1) **Youth in Mind**: Online support website for stressed children and teenagers and those who care for them
   www.youthinmind.info.

2) **MindEd**: Online educational resource on children and young people's mental health. Includes a tutorial on unexplained physical symptoms
   www.minded.org.uk

3) **Royal College of Psychiatrists - Medically Unexplained Symptoms**: information leaflet for patients and carers
   www.rcpsych.ac.uk/mental-health/problems-disorders/medically-unexplained-symptoms

4) **Rethink**: Online support website for everyone affected by mental illness
   www.rethink.org/services-groups

SELF-MANAGEMENT STRATEGIES

1) Stress management leaflet:
   patient.info/health/stress-management

2) Information on Functional Disorders:
   www.neurosymptoms.org/en/

3) Healthy living advice for people living with functional disorder.
   fndhope.org/living-fnd/healthy-living/

4) Relaxation techniques:
   www.nhs.uk/conditions/stress-anxiety-depression/pages/ways-relieve-stress.aspx

5) Online CBT:
   www.moodcafe.co.uk/free-online-behavioural-therapy.aspx

APPENDIX 5 – TEMPLATE LETTERS

GP REFERRAL LETTER

RE:

DOB:

NHS:

Date:

Dear Colleague,

I reviewed the above patient in my outpatient clinic today who presented with the following symptoms.

-

I have investigated them as far as is clinically indicated and no organic pathology has been identified. At the current time, no further investigation is indicated and the mainstay of treatment will be symptom control.

The following investigations have been found to be normal:

-

During our consultation, I created a simple management plan with the patient to aid their symptom control. I am discharging the patient back to your care and would be grateful if you could review them in one month to assess their progress and make any alterations to the management plan.

Should any red flags develop in the future, please do not hesitate to re-refer the patient for further investigation and review.

Yours sincerely,

LETTER DIRECT TO PATIENT AND FAMILY

RE:

DOB:

NHS:

Date:

Dear Parents / Young Person

Thank you for coming to see me in clinic today

As you know, I have been seeing…(child's name)…/you about his/her/your…(description of symptoms in plain English)

And as you also know, we now have back the results of all the investigations I arranged to make sure that we weren't missing any serious underlying illness. This is excellent news and means we were able to get on with planning what we need to do next to make sure that…(child's name)…/you can get back to business/life as usual as soon as possible.

We agreed that I would arrange for…(child's name)…/you to

E.g. see my physiotherapy colleagues

E.g. Return to school on a timetable of increasing hours, starting with attending registration only for the first two days and then building up…

I will review…(child's name)…/you again in …………………'s time on….(date)…/I have arranged for your GP to review… (child's name)…/you after one month to check on progress with this plan.

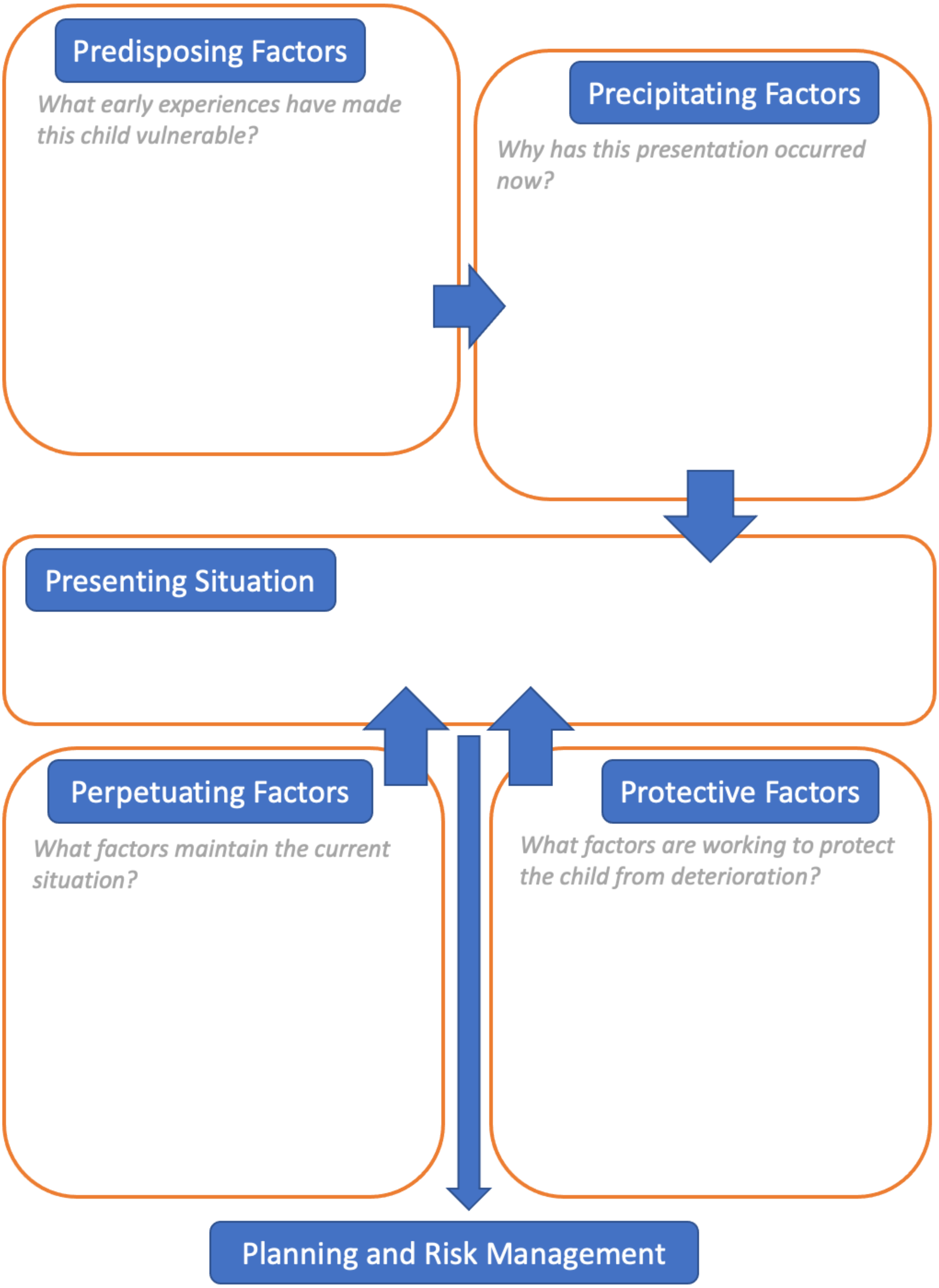
Please feel free to get in contact with me via my secretary if things crop up that make sticking to the plan difficult.

Yours sincerely,

Cc GP

Consider agreeing with CYP/family that school or other agencies are cc'd in e.g. physio.

APPENDIX 6 – FORMULATION AND THE 4 PS



APPENDIX 7 - LEAFLET

Online Resources:

- Stress management leaflet:

patient.info/health/stress-management

- RCPsych information on medically unexplained symptoms:

www.rcpsych.ac.uk/mental-health/problems-disorders/medically-unexplained-symptoms

- Online CBT:

www.moodcafe.co.uk/free-online-behavioural-therapy.aspx

- Relaxation techniques:

www.nhs.uk/conditions/stress-anxiety-depression/pages/ways-relieve-stress.aspx

- Healthy living advice for people living with functional disorder:

fndhope.org/living-fnd/healthy-living/

- Expert patient program:

www.plymouthguild.org.uk

Support services:

- MindEd:

Online educational resource on children and young people's mental health.

www.minded.org.uk

- Youth in mind:

Online support website for stressed children and teenagers and those who care for them.

www.youthinmind.info

BODILY DISTRESS DISORDER

Patient Information Leaflet

What are Bodily Distress Symptoms?

If your doctor has given you this leaflet, then you or someone you know is suffering from Bodily Distress Disorder

BDS can also be described as ‘functional disorders’ and are bodily sensations which cause pain and disability by affecting the normal functioning of the body. Despite adequate medical testing, an illness cannot be found to be causing the symptoms and no underling damage to the body can be seen.

They are common and affect 1 in 10 children.

Common Types of BDS:

- Tummy pain
- Chest pain
- Breathlessness
- Pain on swallowing
- Headaches
- Muscle aches/tiredness
- Difficulty walking
- Bloating
- Diarrhoea
- Vomiting
- Racing heart

Coping with BDS can be difficult and at times the symptoms may impact your whole life. However, the symptoms are likely to resolve or improve over time

What Can My Doctor Do?

The doctor/s you have seen will probably have given you some advice on how to manage and control your symptoms. It can sometimes take a few months for a significant improvement to be seen.

You should be reviewed by your GP in around one month’s time to ensure your symptoms are being as well managed as possible and for any alterations to be made.

If the symptoms persist beyond this it is helpful to schedule regular appointments to your GP for a review and further coping strategies to be considered.

What Can I Do?

Stress and exhaustion can often worsen symptoms so it is important to maintain a healthy lifestyle and look after yourself e.g.

- Do regular exercise
- Maintain a good sleeping pattern
- Eat regular meals
- Maintain a healthy diet
- Minimise stress inducing activities
- Look up coping strategies online (see back of leaflet)
- Visit support groups in the area
- Consider complementary therapies
- Relaxation techniques (see back of leaflet)
- Maintain a positive outlook